



## NEWBORN SCREENING FACT SHEET

### POSITIVE HEMOGLOBINOPATHY SCREENING TEST RESULT FOR SICKLE CELL HEMOGLOBIN C DISEASE

#### WHY DO WE SCREEN BABIES FOR HEMOGLOBINOPATHIES?

Hemoglobin is the chemical inside red blood cells that carries oxygen. Some people have a change in their hemoglobin. In some cases, like sickle cell trait, this causes no problems. In the cases of sickle cell disease or sickle cell hemoglobin C disease babies need early medical attention to prevent serious, or even life-threatening problems.

#### WHAT DOES A POSITIVE SCREENING TEST FOR SICKLE CELL HEMOGLOBIN C DISEASE MEAN?

Hemoglobin, like all other proteins in your body, is made from instructions contained in your genes. Each gene has two copies. Sickle cell trait occurs when one copy of the gene for hemoglobin is abnormal, and there is no disease. If your baby inherits one copy of the gene for sickle cell and one copy of the gene for hemoglobin C then your baby has sickle cell hemoglobin C disease. (People inheriting sickle cell genes in both copies have sickle cell disease).

Screening tests are used to separate those who almost certainly do not have a disease, from those who are more likely to have a problem. Your baby's positive screening test means that additional tests must be done to determine a diagnosis.

#### HOW CAN *SICKLE CELL HEMOGLOBIN C DISEASE* AFFECT YOUR BABY'S HEALTH?

This disease is somewhat like sickle cell disease but clinical problems often are milder. It is a lifelong condition that can cause severe anemia and other problems children with sickle cell disease sometimes get. These problems may include stroke, lung damage, and painful crises. These children are also at risk for serious infection. They need to take antibiotics to lower their risk of infection.

#### WHAT SHOULD A PARENT DO WITH THIS SCREENING TEST RESULT?

In order to find out whether or not your baby has sickle cell hemoglobin C disease, you and your baby's doctor need to discuss the test results and to get additional testing for your baby.

#### WHO CAN I CALL FOR MORE INFORMATION?

You can get more information from your baby's doctor, or you can contact the Hemoglobin Follow-up Program at (402) 559-7257 or (800) 656-3937 for more information. Other Hematology specialists are available at (402) 955-5549 Childrens Hospital in Omaha, or (308) 762-2125 Dr. Howard Koch in Alliance.